



Mission Statement

The goal of the Patient Representative working group is to provide a space for patient representatives and researchers to collaborate, with a focus on improving the patient representative experience and continuing quality improvement.

Group Focus Areas:

1. Patient representative education
2. Patient representative recruitment and retention
3. Quality improvement initiatives within REiNS

Current Members

Member *indicates leadership/ advisory committee
Scott Plotkin, MD (Chair) – Massachusetts General Hospital - SPLOTKIN@mgh.harvard.edu
Alexandra Powers Cellucci
Andrea Gross, MD - National Cancer Institute *
Andres Lessing
Annette Baker
Barbara Franklin
Beverly Oberlander
Brandie Evans
Brigitte Wideman, MD -National Institute of Health *
Cindy Hahn
Claas Rohl
Colleen Marchetti
Connie Sorman
Dale Berg
Dena Hasselberg
Diana Haberkamp
Erickson Gregg
Eva Dombi, MD – National Cancer Institute *
Heather Radke
Herb Sarnoff
Jaishri O'Neill Blakeley, MD – Johns Hopkins University *
Jessica Semblanet
Kallie Enman
Karen Peluso
Karin Walsh, PsyD – Children’s National Medical Center *
Kim Bischoff
Krista Fredrick



Krizelle Alcantara
Maarten de Wit
Mark Bornfeld
Maureen Hussey
Melissa White
Michael Fisher, MD – Children’s Hospital of Philadelphia *
Mikki Montgomery
Nicola Kean
Oliver Hanemann, MD – University of Plymouth *
Onno Faber
Pamela Knight
Pamela L. Wolters PhD – National Institute of Health *
Renie Moss
Roberto da Silva Ribeiro
Rosemary Anderson
Sara Adsit
Stephanie Reeve
Tammy Benson-O'Brien
Traceann Rose – Children’s Tumor Foundation *
Tracy Galloway
Tracy Wirtanen
Vanessa Merker, PhD – Veterans Health Administration *

Meeting Schedule (Coordinator’s contact info): Vanessa Merker at Vanessa.merker@va.gov

Outputs Produced (.pdf reference):

- A. Patient representative educational materials adapted from EUPATI website ([Link](#))
- B. Patient representative survey

Outputs Under Development (Project lead):

- A. Glossary of term for patient representatives
- B. Working group snapshot templates
- C. Manuscript reviewing patient engagement in REiNS activities to date
- D. Internal Survey to evaluate of the patient representative program

Next Major Milestone (Project Lead, Target Date)

The patient representative working group is currently analyzing data from a recent survey of patient representatives to see how we can optimize the REiNS patient representative experience and potentially to share our experience and lessons learned with other advocacy groups.